NEW JERSEY

STATEWIDE COORDINATED STATEMENT OF NEED

AS REQUIRED BY THE RYAN WHITE CARE ACT

SUBMITTED TO:

Health Resources and Services Administration
HIV/AIDS Bureau

SUBMITTED BY:

New Jersey Department of Health and Senior Services
Division of AIDS Prevention and Control
on behalf of
The New Jersey Statewide Coordinated Statement of Need Task Force

November 1, 2001

This document is dedicated,

both in thought and action, to those . . .

who lost their lives to HIV and AIDS,

who continue to live with HIV and AIDS,

who are committed to love and care for anyone with HIV or AIDS,

who work at ending HIV and AIDS in New Jersey and the world!

AMERICANS WITH DISABILITIES ACT (ADA)

The Statewide Coordinated Statement of Need Task Force wishes to state its intent that compliance with all provisions of the ADA should be practiced uniformly in the planning and implementation of Ryan White CARE Act-funded services in New Jersey. Therefore, it is a fundamental understanding of this document that non-compliance with any tenet of the ADA would constitute the foremost barrier to be corrected on behalf of People Living with HIV/AIDS (PLWH/A). The recommendations of this document are put forth with the expectation that measures to implement them be carried out with unimpeded compliance to the requirements of the ADA.

TABLE OF CONTENTS

EXECUTIVE SUMMARY

INTRODUCTION AND EPIDEMIOLOGY

The 2001 Statewide Coordinated Statement of Need (SCSN) builds on the foundation of its 1998 predecessor document in its recognition of the unique dimensions of the epidemic and the array of care and treatment services extant in New Jersey. It also builds on the original document in having incorporated into its preparation information garnered from two surveys the SCSN Task Force undertook of the state's Ryan White community on their knowledge, opinions, and utilization of the first SCSN.

Using an open and inclusive process in ongoing meetings over the last three years, the SCSN Task Force expanded its membership in such areas as incarceration, substance use, and housing, examined needs assessments statewide, and restructured "update" workgroups reflecting the decision to focus SCSN recommendations in the four broad areas of standards and quality of care, access to care, marginalized groups, and managed care.

Epidemiology, based on cumulative counts and rates of both AIDS and HIV from the Division of AIDS Prevention and Control's (DOAPC) Surveillance Unit records, reveals that the estimated 28,838 People Living with HIV/AIDS (PLWH/A) fall heavily into the injecting drug use transmission category. Additionally, both women and Black and Hispanic minorities are disproportionately represented in the epidemic, facts strongly considered in many of the SCSN recommendations. New Jersey's third place ranking nationwide in the number of pediatric AIDS cases likewise influenced this round of SCSN recommendations. Counseling and testing to detect HIV within an extensive network, inclusive of sites allowing anonymity, was reviewed as a corollary to optimum provision of care and treatment services.

FOUR BROAD GOALS

Individuals, providers, and systems within the Ryan White community are asked to strongly consider in their planning and service provision these four broad goals devised to address the barriers, gaps, and needs identified through the collective efforts of the SCSN Task Force.

STANDARDS AND QUALITY OF CARE

To create and facilitate widespread understanding and the application of definitions, standards and quality of care tailored to the specific needs of programs and efforts funded under various Ryan White Titles, as well as those not funded by the Ryan White CARE Act.

ACCESS TO CARE

To increase access to care, paying particular attention to problems in the areas of outreach and referral for hard-to-reach groups, changes in entitlement programs, medical insurance, HIV as a chronic disease, transportation, cultural competency, and language capabilities.

MARGINALIZED GROUPS WITH SPECIAL NEEDS

To increase the effectiveness of planning, involvement, and treatment for IDUs, low-income Black and Hispanic women, their infants and children, incarcerated people, seniors, undocumented/immigrants, youth, orphans to AIDS and their kin, and other groups of PLWH/A with special needs, including links to HIV prevention services for marginalized groups with special needs.

MANAGED CARE

To complement and help enhance Medicaid managed care and other managed care providers' effectiveness in treating HIV/AIDS and serving PLWH/A.

BARRIERS AND GAPS

Barriers and gaps affecting service provision have been thoroughly documented within the four broad goal areas. The additional breakout under their own heading gives them emphasis as the starting point from which the broad recommendations listed under each goal were developed. They reflect deficiencies, limitations, and in a few instances, outright lack of elements fundamental to the facilitation of service utilization by New Jersey's PLWH/A.

Under **Standards and Quality of Care**, examples include:

- Many clinical and support service providers fail to provide services on a family-centered basis;

- Formal comprehensive harm reduction strategies to intervene with IDUs do not exist, nor have the legal barriers to the purchasing and possession of injection equipment been modified or removed;

- African American PLWH/A are underutilizing the pharmaceutical assistance offered by the Title II AIDS Drug Distribution Program (ADDP).

Barriers and gaps under **Access to Care** include:

- Outreach services have deficiencies such as ill-defined linkages to HIV counseling and testing, non-inclusion of outreach staff on treatment teams, insufficient training of outreach workers, and decentralized referral mechanisms;

- Cultural incompetence and monolingualism within provider organizations contribute to some PLWH/A not accessing services.

Within **Marginalized Groups with Special Needs**, deficiencies include:

- A lack of understanding of addictions and mutual mistrust between IDUs and service providers hamper provision of services to IDUs;

- Low income Black and Hispanic women pose particular challenges regarding their involvement in planning, prenatal care, and medical treatment, often because self-care may be a lower priority for them than spouse or child care;

- Immigrants and undocumented persons experience barriers to accessing care due to fear regarding Immigration and Naturalization Service (INS) concerns and little information about medical services for which they qualify.

Regarding **Managed Care,** concerns include:

- PLWH/A have been confronted with barriers to seamless utilization of their HIV specialists in the transition to Medicaid managed care due to such problems as auto-assignment into unaffiliated plans and relatively low proportions of specialists available within contracted HMOs.

BROAD GOAL RECOMMENDATIONS

The **Standards and Quality of Care** goal was analyzed in relation to care provision to three populations and within fourteen service categories funded under Ryan White. These include: adults, women, and children/adolescents; substance use treatment; case management; dental/oral health services; hospice; home health care; mental health services; pharmaceutical assistance; legal advocacy; direct emergency financial assistance; food/meals/nutritional services; education and training; housing related services; complementary therapies; and day and respite care. Recommendations focus around improvement of quality of care utilizing standardized practices in treating the noted populations and implementing the various categorical services.

Recommendations include:

- All standards of care should be implemented and administered effectively by the grantees and project administrators so that funded agencies are held accountable for their adherence to applicable standards;

- The Perinatal Rapid Testing Initiative coalition should promptly complete and facilitate implementation of the statewide policy for rapid testing, results counseling, and short course antiretroviral therapy to be utilized with women who present in labor with unknown serostatus. The coalition should work to garner the cooperation of hospital emergency rooms to enable the implementation of the policy;

- Recognized standards of care for oral health should be promulgated by the appropriate federal authority, widely disseminated, and incorporated universally in dental and medical practices;

- The Title II grantee should institute measures to rectify the comparatively low participation of African Americans in the AIDS Drug Distribution Program. Standardized outreach protocols should be established to utilize face-to-face helping contacts in a number of settings to enroll African Americans in the program;

- The DOAPC, the Department of Community Affairs (DCA), and other housing-related administrators and stakeholders should collaborate to lessen affordable housing shortages and reduce barriers to PLWH/A in accessing housing, such as procedural delays and inadequate coordination between HOPWA and non-Ryan White housing/shelter programs.

The **Access to Care** goal was analyzed conceptually as to overall factors influencing service utilization by PLWH/A, such as the transition of HIV infection and even AIDS to a chronic

disease model, and the relative levels of cultural competency and multi-language capabilities among service providers. It was also reviewed as to six concrete service categories, including financial entitlements, medical insurance, outreach, information/referral, HIV counseling and testing, and transportation.

Recommendations include:

- Any individual diagnosed by CDC standards as having HIV disease, who is currently on Highly Active Antiretroviral Therapy (HAART), should not be terminated from Social Security during the initial period of the regimen when assessment of prolonged improvement of health status and abilities of daily living is still underway;

- While PLWH/A with improved health are being re-evaluated for SSI eligibility, Medicaid should provide a transitional period of health insurance (Medicaid) until their employer-provided health insurance coverage becomes effective;

- Identify outreach and referral "best practices" and provide outreach workers with uniform training in outreach and referral strategies and techniques for involving PLWH/A from hard-to-reach groups, such as substance users and others. Train outreach workers in note taking, documentation, communication skills, cultural sensitivity, harm reduction, resource identification, and follow-up of care plans;

- Planning bodies should consider establishing centralized referral efforts which include core resources, such as legal advocacy;

- Staff at sites where HIV counseling and testing is performed should routinely include as one of their core linkages for HIV+ clients referrals to mental health and/or other counseling;

- Title I EMAs and Title II Consortia should re-evaluate the current transportation delivery system to determine its effectiveness and impact on the HIV/AIDS

community, and scattered transportation sites should be considered, with each provider required to include at least one out-of-county destination in its proposal;

- Provide for cultural competency and cultural sensitivity in the hiring and appointing of people to carry out planning and service delivery;

- Prepare written materials in appropriate literacy levels and have translations into various languages, reviewed, and edited by individuals of the native language.

The **Marginalized Groups with Special Needs** goal includes six populations, injecting drug users (IDUs), low-income Black and Hispanic women (and their infants and children), incarcerated/recently released people, seniors, undocumented/immigrants, and youth/orphans to AIDS (and their kin). The review of these populations also focused special attention on HIV prevention and special needs groups.

Recommendations include:

- Involve representatives of IDUs, low-income Black and Hispanic women, incarcerated people, seniors, immigration advocates, youth, orphans and their kin, and other groups with special needs in planning, implementing, and evaluating training and service delivery targeted to those groups;

- Expand the availability of substance use treatment facilities and outpatient programs so that sufficient treatment slots, support groups, and interventions designed for youth and young adults may be targeted to IDUs with HIV/AIDS;

- Enhance care and treatment service delivery in such ways as co-location of adult and pediatric medical services, flexible program hours, i.e. evenings, weekends, and concrete services such as transportation and childcare;

- Continue intensive efforts to engage pregnant women in prenatal care via such interventions as van outreach in targeted cities, and refinement of protocols for HIV testing and provision of HAART prenatally and during labor/delivery for the further reduction of perinatal HIV transmission;

- Encourage and promote "Inreach" efforts (on-site services within various correctional institutions) by public health agencies and community based organizations whereby their services are extended to soon-to-be-released inmates at all institutional levels;

- Clinicians treating seniors should take sexual and drug use histories and include HIV prevention messages and other appropriate interventions in their care plans for senior patients;

- Design a strategy to address the perceived and real costs charged for health care, that now preclude persons from accessing care, which would maximize the utilization by immigrants and the undocumented of existing programs for which they are financially eligible;

- Inform policymakers that youth are making "adult" decisions before reaching their majority, and they should be afforded information regarding their health, benefits, and support services, and permitted to make decisions without the signed waivers, consents, and/or the presence of guardians, if necessary. This should include access to HIV counseling and testing without parental/guardian consent for those under the age of 18;

- Children orphaned to AIDS and placed with kin should be afforded the same stipends and services given to children placed in foster care;

- Co-locate prevention programs and Ryan White care and treatment programs to ensure the involvement of HIV prevention case managers and health educators in treatment planning for marginalized PLWH/A with special needs.

The **Managed Care** goal was analyzed as to the transition of Medicaid patients with HIV into contracted HMOs and its impact on the continuity of HIV specialty care for those affected PLWH/A.

Recommendations as to the ongoing collaboration of the Department of Health and Senior Services (DHSS) with the Department of Human Services (DHS) Medicaid Office of Managed Health Care include:

- Ensure that the federal standards of care for PLWH/A (adult, women, and pediatric) are adhered to through established agreements with MMC companies to utilize existing centers of treatment excellence, including following HIV-exposed infants and HIV infected children and youth at a pediatric HIV network site;

- Address the issues and barriers resulting from "auto-assignment," through the identification of the process (including responsible individuals at each level) to quickly resolve grievances and complaints from PLWH/As, so that access to appropriate care is not interrupted or stopped;

- Compile and make available to MMC companies and PLWH/A up-to-date lists of all HIV experienced primary care providers (not just infectious disease specialists) in each catchment area, including those experienced in treating women and children, qualified dental health providers, as well as appropriate advocacy/grievance procedures and resources;

- Planning councils and planning bodies, including consumer groups and consortia, should work to establish local and regional liaisons and working relationships with MMC and other managed care systems and providers.

CONCLUSIONS

The continuance within this document of the four broad goals from the 1998 SCSN, albeit with modified recommendations under them, speaks to their discerned validity among Task Force participants in fostering quality care and treatment for PLWH/A in New Jersey. It is the intent of this document that barriers and gaps discussed herein may be lessened in number and narrowed in scope by an honest review and sincere application on the part of HIV community stakeholders of the recommendations of this document. SCSN recommendations form the ideal around which programs and services for PLWH/A need to be devised for the steady improvement in the continuum of HIV care for New Jersey's communities.

INTRODUCTION

This Statewide Coordinated Statement of Need (SCSN) augments its predecessor document developed in 1998, in defining current goals and recommendations to be used by participants in all five Ryan White Titles in their ongoing planning and implementation of Ryan White-funded services.

BACKGROUND

The HIV/AIDS epidemic continues to have a devastating impact on New Jersey. As of December 31, 2000, the New Jersey Department of Health and Senior Services reported 28,838 New Jersey residents living with HIV/AIDS. Disproportionate numbers of injecting drug users (IDUs), people of color, women and children are still hardest hit by the epidemic. IDUs represent 36.6% of overall HIV/AIDS cases, while New Jersey remains fifth in the United States in the number of AIDS cases, third in the number of pediatric AIDS cases, and first in the percentage of women with HIV/AIDS.

In response to the epidemic, a sophisticated and comprehensive array of care and treatment services evolved in New Jersey. These have been enabled by private foundation, state and, in the last ten years, Ryan White CARE Act funds. Assessment of the ongoing and emerging needs of HIV-infected citizens has been continual in attempting to appropriately allocate available resources where they can work to the best advantage for people living with HIV/AIDS (PLWH/A) in the state.

The 1998 SCSN was designed to enhance coordination across various CARE Act Title programs and grantees. In 1999, shortly after the broad dissemination of the SCSN to New Jersey's "AIDS community," a survey conducted by the SCSN Task Force retrieved encouraging responses to its questions on the utility of the document. Thirty-seven percent of eighty-eight key informants responded. Of those 89% affirmed familiarity with the SCSN. The same proportion ranked the importance of the SCSN in planning activities from slightly to very important. Regarding the use of the SCSN, 89% confirmed that SCSN recommendations were used in the current service delivery plan, while 95% professed intent to use the SCSN within the next planning year.

THE PROCESS

Under the coordination of a DHSS staff member, the SCSN Task Force continued to meet on a monthly basis even after the submission of the SCSN to the Health Resources and Services Administration (HRSA) in March 1998. This was by decision of Task Force members, who saw a need to extend the collaborative process put in place to develop the document. They first established objectives and activities to ensure wide dissemination of the SCSN and utilization of its recommendations in planning among CARE Act principals.

Between June and August 1998, the DHSS Coordinator, along with members of the Task Force, presented standardized overviews of the SCSN scripted by a Task Force committee. These were provided at meetings of Title I Planning Councils, Title II Consortia, Title III sites, and the Title IV Network. In follow-up to a general mailing of the document to all known AIDS community organizations, accomplished between March and June 1998, individual copies of the SCSN were provided to each person attending a presentation. This facilitated attendees' understanding of the contents of the SCSN and two-way discussion on the utility of the document in their targeted planning processes.

The Task Force Feedback and Implementation Committee, between September and December 1998, developed and implemented the key informant survey questionnaire alluded to under "Background." This assessment of the implementation of the SCSN formed a focal point of a Task Force-sponsored all Titles meeting in May 1999. A second, corollary objective of the well-attended conference was education on outcome evaluations, featuring national-level speakers and local trainers leading experiential workshops.

Subsequent monthly Task Force meetings were devoted to mapping out a systematic process for the HRSA-mandated third-year update of the SCSN. These collaborations enabled: refining of membership to ensure balanced and inclusive representation and enhanced expertise on incarceration, substance use and housing; networking with HRSA principals and other high HIV-incidence states on guidance in modifying the SCSN; establishment of restructured "update" committees; review of current needs assessments of Title I and II planning bodies; and conduct

of a second survey to the AIDS community in 2000 seeking recommendations in updating the SCSN.

Based on information garnered, Task Force members formed five work groups. These reflected, in part, the continued categorization of SCSN recommendations within topic areas identified in the 1998 document; namely, Managed Care, Marginalized Groups, Access to Care, and Standards and Quality of Care. The fifth, the Editorial Work Group, as with the first SCSN, integrated reports from the four topical work groups into this updated SCSN.

TASK FORCE REPRESENTATION

The SCSN Task Force includes representatives from the five Ryan White Titles, as listed in Appendices A and B. Other representation noted in those listings includes the New Jersey HIV Prevention Community Planning Group, the Governor's Advisory Council on AIDS, the Kinship Care Interdepartmental Work Group, Housing Opportunities for People with AIDS (HOPWA), the New Jersey Department of Corrections, community-based organizations (CBOs), PLWH/A, and medical, administrative and social services providers. Task Force membership is racially, ethnically, and geographically diverse and reflects the demographics of PLWH/A in New Jersey.

EPIDEMIOLOGICAL PROFILE OF HIV/AIDS IN NEW JERSEY

This profile shows data for the state of New Jersey through December 31, 2000 and makes comparisons to the nation for the same time period. It also compares data with the prior year, ending December 31, 1999.

CUMULATIVE COUNTS AND RATES OF AIDS AND HIV

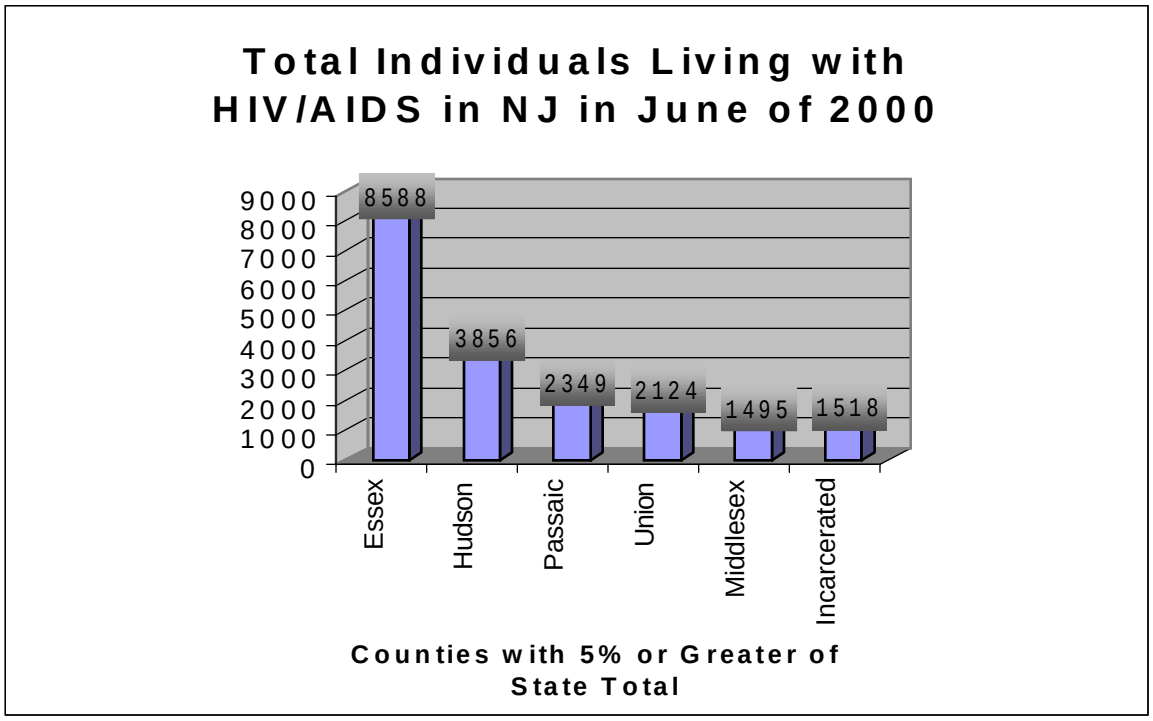
New Jersey ranks fifth in the U.S. in reported AIDS cases. During the period December 31, 1999 to December 31, 2000, 1,858 New Jersey resident AIDS cases were verified and entered in the HIV/AIDS Reporting System (HARS). This is an increase of 4.1%. The HARS is maintained by the Surveillance Unit of the Division of AIDS Prevention and Control (DOAPC) of the New Jersey Department of Health and Senior Services (DHSS). Cumulative resident AIDS cases reported in the HARS as of December 31, 2000 numbered 41,290, a 4.7% increase from the prior year.

From December 31, 1999 to December 31, 2000, 346 HIV cases were added to HARS, an increase of 2.3%. Cumulative HIV infection reports of New Jersey residents in the HARS as of the end of December 2000 numbered 15,214. These counts of HIV reports do not include 12,187 patients originally reported with HIV infection who have progressed to AIDS and are currently counted as AIDS cases.

PEOPLE LIVING WITH HIV/AIDS

From the December 31, 2000 reporting period, the DOAPC calculates that New Jersey now has 28,838 People Living with HIV/AIDS (PLWH/A) in the state, an increase of 1,238 or 4.5%.

Historically, this state has had the highest percentage of women living with AIDS of any state in the country. As of December 2000, women accounted for 28% of the total reported New Jersey cases of AIDS. This is the same as the prior year. Nationwide, the proportion of women AIDS cases to total was 17.4%.



GEOGRAPHIC DISTRIBUTION OF PLWH/A IN NEW JERSEY

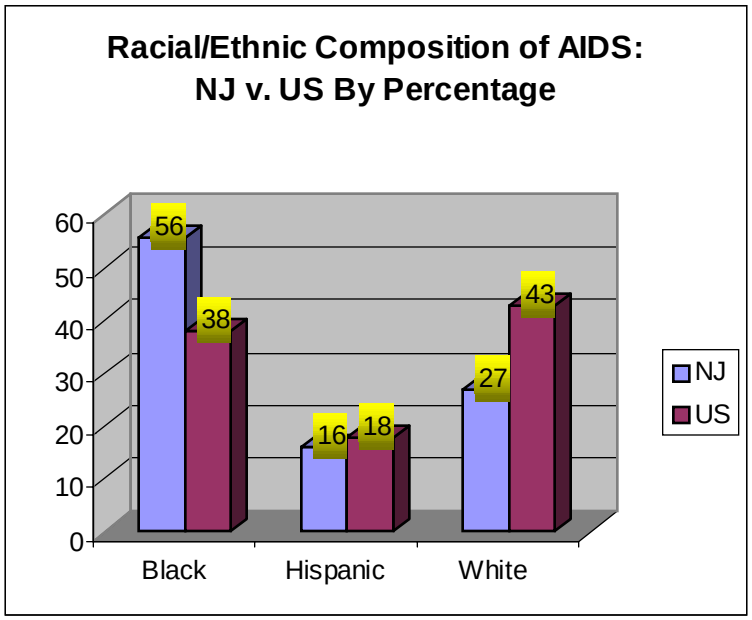
The northeastern Counties of Essex and Hudson are the two most impacted by HIV/AIDS of the twenty-one counties in the state.

Essex County reported an additional 201 cases living with HIV/AIDS in the period ending December 31, 2000, 5,499 total cases in 2000 vs. 5,298 total cases in 1999. Hudson County experienced 134 more cases in this time period, rising from 2,222 cases in 1999 to 2,356 cases in December of 2000. Together, these two counties account for 27% of all the PLWH/A in the State and represented 27.1% of the increased cases in the State.

RACIAL/ETHNIC DISTRIBUTION OF AIDS IN NEW JERSEY

Blacks and Hispanics are disproportionately affected by AIDS in New Jersey. According to the 2000 U.S. Census, Non-Hispanic Blacks are 13.7% of the state's total population, but were 56% of the reported AIDS cases as of December 31, 2000. Similarly, Hispanics are 13.3% of New

Jersey's population in 2000 Census counts, but accounted for 16% of the reported AIDS cases as of December 31, 2000.



Nationally during the last year, Blacks with AIDS increased from 37.2% to 37.8% of the total, Hispanics increased from 18.2% to 18.3%, and Non-Hispanic Whites decreased from 43.4% to 42.8% of the total. For the state of New Jersey, as of December 31, 2000, Non-Hispanic Blacks comprised 56.1% of the AIDS population, followed by non-Hispanic Whites at 27%, and Hispanics at 16%. These percentages were the same as the prior year.

AGE OF INFECTION FOR THOSE LIVING WITH HIV/AIDS IN NEW JERSEY

When viewed by age at diagnosis of HIV/AIDS, two age groups showed decreases in the number of PLWH/A from December 1999 to December 2000. The first of these age categories was "Less than 5 years" which went from 1,029 cases in December of 1999 to 567 cases as of December 2000. This represents a 44.9% decrease. The other category was Age Group 20-29 which decreased from 1,930 to 1,777 cases, or 7.9%. Two age categories, "40-49" and "Over 49," evidenced significant increases, going up by 10% and 23.3%, respectively. As of December 31, 2000, these two groups represented 56% of the total cases of PLWH/A in the state of New Jersey.

MODE OF TRANSMISSION

Virtually all modes of transmission for the adult/adolescent population of PLWH/A in New Jersey saw increases between December 31, 1999 and December 31, 2000. The one exception, the "Coagulation Disorder" category, decreased by one case.

"Men Having Sex with Men (MSM)" increased by 8.2%. This category represented 16.5% of the cases.

"Heterosexual Contact" experienced an increase of 10.7%. For this transmission mode, males had an increase of 12.7%, and females increased by 9.7%. In both 1999 and 2000, females represented two thirds of the cases of those who had acquired HIV/AIDS through heterosexual contact.

The number of adults/adolescents who reported IDU as the mode of transmission increased by 2.6%. Injection Drug Users (IDUs) was the most common transmission category as of December 2000, representing 36.6% of the total PLWH/A. This number reflects a 1.3% decrease in the percentage of the total PLWH/A from the prior year. In 2000, males accounted for 65.7% of the IDUs, and females accounted for 34.3%. These were approximately the same percentages as in the prior year.

PERINATAL HIV/AIDS IN NEW JERSEY

New Jersey ranks third among the states in the number of children under 13 who are living with HIV/AIDS, which stands at 499 cases, or 11.9% of the total reported cases. This ranking is unchanged from the prior year.

This state was also third in the number of reported pediatric AIDS cases. Through December 31, 2000, there were 733 cases. Of these, 693, or 95%, had a transmission mode listed as “Mother With or at Risk of AIDS." Epidemiological data suggest transmission occurs from an infected mother to her fetus or infant during the prenatal period or at birth. The success of the "O76" Protocols, adopted in 1993 to reduce the transmission of HIV from mother to newborn, is evident

from the data. For children born in 1993 with HIV/AIDS, the infection rate was 21.1%. For children born in 2000, the transmitted infection rate diminished to 3.3%.

HIV COUNSELING AND TESTING IN NEW JERSEY

Testing for HIV infection in conjunction with pre- and post-test counseling of those tested has been comprehensive in scope and an important component of HIV epidemiological profiling in New Jersey.

The DOAPC has established an extensive counseling and testing network in the state, consisting of 200 active sites. Since 1997, the number of tests performed within this network has decreased from 63,381 in 1997 to 57,799 in 2000, a decline of 8.8%. The rate of HIV seropositivity also decreased from 3.05% (1,936 HIV+) in 1997 to 2.52% (1,458 HIV+) in 2000.

Fifteen of the sites within the network are designated to offer both anonymous and confidential testing. The DOAPC strongly supports the ongoing encouragement of confidential testing at these sites so that clients testing positive, who are accessible to test site counselors via their confidential identifiers, may be notified of their positive test results and provided referral linkages into prevention and treatment services. From 1997 through 2000 anonymous testing has declined steadily both as raw numbers and as percentages of all tests performed: 6,528 or 10.3% in 1997 vs. 3,295 or 5.2% in 2000.

FOUR BROAD GOALS

BROAD GOAL FOR STANDARDS AND QUALITY OF CARE

To create and facilitate widespread understanding and the application of definitions, standards and quality of care tailored to the specific needs of programs and efforts funded under various Ryan White Titles, as well as those not funded by the Ryan White CARE Act.

BROAD GOAL FOR ACCESS TO CARE:

To increase access to care, paying particular attention to problems in the areas of outreach and referral for hard-to-reach groups, changes in entitlement programs, medical insurance, HIV as a chronic disease, transportation, cultural competency, and language capabilities.

BROAD GOAL REGARDING GROUPS WITH SPECIAL NEEDS:

To increase the effectiveness of planning, involvement, and treatment for IDUs, low-income Black and Hispanic women, their infants and children, incarcerated people, seniors, undocumented/immigrants, orphans to AIDS and their kin, youth, and other groups of PLWH/A with special needs, including links to HIV prevention services for marginalized groups with special needs.

BROAD GOAL REGARDING MANAGED CARE:

To complement and help enhance Medicaid Managed Care (MMC) and other managed care providers' effectiveness in treating HIV/AIDS and serving PLWH/A.

BARRIERS AND GAPS

The following barriers and gaps were garnered from the narratives that follow for the Four Broad Goals. They are listed together here to convey the issues and problem areas addressed by the recommendations of this document.

- Some local EMAs have been unable to develop standards of care and service descriptions due to limitations of administrative and fiscal resources.

- Kin and other caregivers of orphans to AIDS, including HIV-infected children, have special needs, impacted by limited financial resources, problematic housing arrangements, fragmented support services, and minimally responsive educational systems.

- Many clinical and support service providers fail to provide services on a family-centered basis.

- Maximal reduction of perinatally transmitted HIV infections is hampered by health care delivery systems' inability to determine a woman's serostatus in labor and delivery, and if her status is unknown, provide HIV counseling and offer rapid or expedited testing so that appropriate antiretroviral prophylaxis may be applied.

- Formal comprehensive harm reduction strategies to intervene with IDUs do not exist, nor have the legal barriers to the purchasing and possession of injection equipment been modified or removed.

- Need for drug treatment continues to outweigh the number of treatment slots available with resultant waiting lists.

- Case management providers need continued education to maintain improved engagement of PLWH/A in their care plans and to meet the new challenge of the transition of all Medicaid recipients to managed care HMOs.

- Dental care and oral health maintenance are hampered by poor provider capacity, limited funding to dental services, proximity and availability of adult and pediatric providers, and unresponsiveness to requests for proposals from dentists in certain catchment areas. Other impeding factors are: inadequate physician education regarding the oral health component of a treatment plan; Medicaid managed care HMOs' lack of affiliation with HIV-dedicated dental treatment programs; low Medicaid reimbursement rates for complex HIV-related dental care; inadequate adherence to recognized standards of care for oral health; and ineffective client education on maintaining good oral health through existing dental services.

- African American PLWH/A are underutilizing the pharmaceutical assistance offered by the Title II AIDS Drug Distribution Program (ADDP).

- PLWH/A need enhanced legal assistance and advocacy for problems with discrimination, permanency planning, adoptions/foster care, housing, entitlements, managed care, and domestic violence.

- PLWH/A have periodic, emergent reductions in income affecting their adherence stability, activities of daily living, and abilities to maintain health care interventions and pharmaceutical regimens.

- Many PLWH/A fail to acquire food and maintain adequate nutritional intake due to many barriers to the implementation of food service programs. The barriers include ineffective information dissemination, problematic referral linkages, prohibitive eligibility processes, lack of refrigeration and cooking facilities, and lack of transportation and/or childcare.

- PLWH/A have insufficient emergency transitional and supportive housing units available to them, and they experience access problems due to procedural delays, including prerequisite mental health screenings, inadmissibility of active substance users, and lack of coordination with non-Ryan White housing/shelter programs.

- Medical providers have a pervasive misunderstanding of the usefulness of complementary therapies, such as chiropractic, acupuncture, and massage, for pain management and other applications in the continuum of patient care.

- "HIV Specialist" needs an agreed-upon definition acceptable to the New Jersey medical community, inclusive of clinicians and insurers.

- Primary caregivers have insufficient relief from their daily responsibilities of providing care for PLWH/A, their children, partners, and/or other family members.

- PLWH/A are hampered in accessing care due, in part, to changes in entitlement programs, the varying quality and effectiveness of outreach and referral services, fragmented availability of transportation, uneven levels of cultural competency and multilingualism, and the relative unresponsiveness of service delivery systems, including insurance, to the changing health outlook with HIV becoming a manageable chronic illness.

- Innovative approaches to the continuing eligibility for entitlement programs, including financial assistance and medical insurance coverage, for PLWH/A with improved health status are needed to ensure ongoing financial stability and access to medical care.

- PLWH/A with drug convictions, who are excluded by the Welfare Reform Act from financial assistance and other benefits, need interventions to avail them some legal means of support.

- Outreach services have deficiencies such as ill-defined linkages to HIV counseling and testing, non-inclusion of outreach staff on treatment teams, insufficient training of outreach workers, and decentralized referral mechanisms.

- Transportation remains a barrier for PLWH/A' access to services, particularly in keeping out-of-county and off-hours (evenings and weekends) appointments.

- Cultural incompetence and monolingualism within provider organizations contribute to some PLWH/A not accessing services.

- Special needs PLWH/A, such as IDUs, low income Black and Hispanic women and their infants and children, incarcerated people, seniors, undocumented/immigrants, youth, and orphans to AIDS and their kin, require educated, targeted approaches and interventions to engage and maintain them in services.

- A lack of understanding of addictions and mutual mistrust between IDUs and service providers hamper provision of services to IDUs.

- Low income Black and Hispanic women pose particular challenges regarding their involvement in planning, prenatal care, and medical treatment, often because self-care may be a lower priority for them than spouse or child care.

- Quality, frequency, and consistency of HIV-related services for incarcerated PLWH/A vary among county and state institutions in such areas as HIV detection, availability of prevention activities and substance use treatment, prenatal and perinatal care, access to HAART, pain management, terminal or hospice care, and coordinated release planning.

- Barriers to seniors being targeted and receiving care are many and include misconceptions on their sexuality and alcohol/drug use.

- Immigrants and undocumented persons experience barriers to accessing care due to fear regarding Immigration and Naturalization Service (INS) concerns and little information about medical services for which they qualify.

- Barriers in addressing the needs of youth around HIV include abstinence only vs. comprehensive sexuality education, pregnancy concerns, inability to HIV test without parental consent, drug use and criminal behavior, and financial need of PLWH/A from this group reaching adulthood.

- Children/youth orphaned because of AIDS and the kin caring for them face challenges regarding overall sustenance, housing, and needed social services, in part because of the ill-defined relationship between children and kin caregivers and ensuing complications for medical and social service delivery.

- Too little time and effort has been expended in the past on primary prevention targeted to PLWH/A.

- PLWH/A have been confronted with barriers to seamless utilization of their HIV specialists in the transition to Medicaid managed care due to such problems as auto-assignment into unaffiliated plans and relatively low proportions of specialists available within contracted HMOs.

STANDARDS AND QUALITY OF CARE

There is a continuing pressing need for definitions, standards, and quality of care throughout the state between Ryan White and non-Ryan White-funded programs and efforts. The development of standards of care and service descriptions is intended to create a statewide healthcare and social services delivery system that will provide a constant level of quality care for all people living with and affected by HIV throughout the state. Over the past three years, a number of Title I EMAs have developed standards of care and service descriptions, while others continue to be challenged by limited administrative and fiscal resources.

Regarding primary medical care for HIV, the DHSS periodically disseminates updates of its "Guidelines for the Medical Management of HIV/AIDS," most recently the September 2001 issue. These are excerpted and simplified from the "Guidelines for the Use of Antiretrovirals in HIV Infected Adults and Adolescents" issued by the Panel on Clinical Practices for Treatment of HIV Infection, convened by the United States Department of Health and Human Services and the Henry J. Kaiser Family Foundation. The Guidelines form the basis for standardized medical services for PLWH/A statewide.

To further the development of standards of care, information sharing and collaboration are needed among Ryan White and non-Ryan White funded service providers. As the CARE Act upholds the local planning autonomy of Title I and Title II catchment areas, it is not within the scope of the SCSN Task Force to develop common definitions and/or standards. However, the Task Force will work to facilitate the establishment of an information sharing mechanism utilizing the Internet wherever possible.

BROAD GOAL FOR STANDARDS AND QUALITY OF CARE

To create and facilitate widespread understanding and the application of definitions, standards and quality of care tailored to the specific needs of programs and efforts funded under various Ryan White Titles, as well as those not funded by the Ryan White CARE Act.

STANDARDS OF CARE

Recommendations:

- Planning bodies and project administrators should prioritize as the standard of care the implementation of holistic healthcare delivery systems, which utilize multidisciplinary teams to coordinate primary medical care, specialty care, supportive services, psychosocial needs, and research-based interventions.

- All standards of care should be implemented and administered effectively by the grantees and project administrators so that funded agencies are held accountable for their adherence to applicable standards.

- Planning bodies and project administrators should continue to develop codes of ethics and processes for handling client grievances including notice of this right to consumers by all providers and planning bodies.

- Standards relative to privacy issues, conflict of interest, and inappropriate disclosure of information should continue to be paramount to all statewide planning bodies.

- EMAs should provide access to their local standards and definitions and communicate such availability to the DHSS' Title I Liaison.

- In support of Ryan White service provision statewide the DHSS should facilitate the adoption of definitions and standards of care that provide common baselines and also

allow for local individualization of services. Areas for such priority setting, definition, and standard-setting include:

- Prenatal, pediatric, and adolescent care;
- Perinatal transmission interventions;
- Substance use treatment counseling;
- Case management;
- Dental and oral health;
- Hospice;
- Home health;
- Mental health;
- Pharmaceutical assistance;
- Client advocacy/legal services;
- Direct emergency financial assistance
- Food banks/home delivered meals/nutritional services;
- Education/training;
- Housing assistance;
- Complementary therapies;
- HIV specialty care;
- Day/respite care.

QUALITY OF CARE

MEDICAL AND SUPPORT SERVICES

Numerous accomplishments have been made statewide since the development of the 1998 SCSN document. Conversely, several areas of concern and additional barriers to quality of care have been articulated. Following are summary statements regarding barriers and needs in key service categories that should be considered in efforts to improve quality of care. The recommendations that also follow are set forth for consideration by local planners and project administrators when developing standards of care where none exist and to encourage expansion of existing standards to improve quality of care.

PRENATAL, PEDIATRIC, and ADOLESCENT CARE:

Specialized services are increasingly needed for women, children, and adolescents. Women and children continue to be profoundly impacted by HIV and AIDS. New Jersey ranks first in the percentage of women diagnosed with AIDS within the United States and third in the number of pediatric AIDS cases. Of the total AIDS cases reported in New Jersey, women represent 28%, and approximately 33% of all newly diagnosed AIDS cases in people over 12 years of age within the state are female[v].

The emerging problem of AIDS' orphans complicates provision of quality care to this population. Organizations working on behalf of children and HIV-affected families, such as the New Jersey AIDS Partnership's Orphans to AIDS Committee and the New Jersey Resource Foundation for Children, are working with estimates as high as 16,400 children currently orphaned or made motherless by AIDS in New Jersey and projections as high as 18,000 such children by 2002.

Kin/caregivers of orphans have special needs due to limited financial resources, housing problems, and inadequate general support. A growing number of grandparents and other kin are raising preschool and school age children, some of whom are HIV-positive or living with AIDS. Services and appropriate education to both the children and the kin caretakers are needed. School systems need assistance in fostering sensitivity on this issue in teachers and other personnel. Recommendations specific to these kinship needs are contained under Marginalized Groups with Special Needs.

An extensive HIV service delivery system is required to meet the needs of infected women of childbearing/childrearing ages and of infected, exposed, and affected children and adolescents. Unfortunately, service providers are not always sensitive to the needs of children and their caregivers, and fail to provide services on a family centered basis to address the care of children from infancy through adolescence and onto adulthood.

Recommendation:

- Adult and pediatric providers throughout the state should engage in meaningful collaboration to establish standardized family-centered systems of care by consulting the model of the New Jersey Statewide Family Centered HIV Care Network, which unites health and social service providers at the state and local level.

PRENATAL CARE/PERINATAL TRANSMISSION

Perinatal transmission is the predominant mode of HIV transmission for children. Barriers to achieving the elimination of perinatal transmission continue to exist among the healthcare delivery system at large and in the prevention community. It is estimated that approximately 25% of HIV infected women in New Jersey do not get prenatal care, placing their unborn children at risk and vulnerable for HIV infection[vi]. The Title IV Family Centered HIV Care Network has assisted in the reduction of perinatal transmission from 8% in previous years to 3.3% in 2000. Efforts have been made statewide toward the elimination of perinatal transmission. They include the development and implementation of mobile outreach programs targeted to high-risk women in Jersey City, Paterson, and Newark, and the formation of the Perinatal Rapid Testing Initiative. This is a collaborative research effort among the Title IV Family Centered HIV Care Network, the Maternal and Child Health Consortia, and the New Jersey Department of Health and Senior Services (DHSS). The Initiative's objective is the development of a statewide policy for rapid testing, results counseling, and short course antiretroviral therapy to be utilized with women who present in labor with unknown HIV serostatus.

Recommendation:

- The Perinatal Rapid Testing Initiative coalition should promptly complete and facilitate implementation of the statewide policy for rapid testing, results counseling, and short course antiretroviral therapy to be utilized with women who present in labor with unknown HIV serostatus. The coalition should work to garner the cooperation of hospital emergency rooms to enable the implementation of the policy.

SUBSTANCE USE TREATMENT/COUNSELING:

Injecting drug use (IDU) has been and continues to be the primary mode of transmission of HIV infection in New Jersey. Approximately 51%[vii] of all reported AIDS cases in New Jersey are the result of IDU transmission, and the figure is expected to rise. Recent treatment admissions data indicate that injection drug use is on the rise. Statewide substance use prevention to youth, adolescents, and pregnant women is inadequate. Consideration of emerging substance use risk populations, such as athletes who use steroids and users of "recreational" drugs, poses additional challenges. New Jersey lacks formal comprehensive harm reduction strategies, and has not instituted measures to legalize purchase and ownership of injection equipment. Alternative treatment modalities, like acupuncture, are rarely available to New Jersey citizens, unless they are willing to travel to New York City.

The 300+ substance use treatment programs available throughout the state are all at full patient capacity with extensive waiting lists. Need continues to outweigh resources. IDUs historically do not avail themselves of programs or services unless the programs and services are specifically targeted to their treatment and harm reduction needs.

Substance users need assistance to remain engaged in their own HIV care and treatment, and to adhere to their medication regimens. Medical providers are challenged in prescribing antiretroviral regimens that are not contraindicated in methadone-treated patients.

Recommendations:

- Additional substance use treatment facilities, outpatient, and detoxification programs accessible to PLWH/A should be established. Standards for individualized substance use interventions are recommended within a broader range of treatment/rehabilitation options including: long term therapeutic communities; inpatient detoxification programs; out-patient support services; harm reduction programs; PLWH/A-dedicated support groups; programs tailored to youth and pregnant women; complementary therapies such as acupuncture and hypnosis; and dietary/nutritional programs.

- Standardized education, applied in a cross-training methodology to HIV specialty and substance use programs, must include instruction on interventions to maintain active substance users in HIV care and treatment, and measures to assess and address contraindications resulting from methadone treatment and antiretroviral regimens.

CASE MANAGEMENT SERVICES:

The New Jersey AIDS Education and Training Center (NJAETC) through its Newark Title I EMA Targeted Provider Education Demonstration Project (TPED) has provided quality case management training which has enhanced communication of local standards of care and resulted in increasingly improved case management services statewide. Duplication of services has been reduced. Providers need continuing education to maintain and enhance these marked improvements and promote ongoing collaboration. Case managers, the gatekeepers for Ryan White-funded services, need support in engaging PLWH/A in the development of their care plans and clarifying for clients the benefits and role of case management services.

New challenges faced by case management include the transition of all Medicaid patients to managed care HMOs and the need to maintain and insure confidentiality as new systems are developed and implemented.

Recommendation:

- To maintain improvements in case management services and enhance case managers' abilities to assist with Medicaid managed care issues, the NJAETC should provide continuing education and training targeted to case managers.

DENTAL AND ORAL HEALTH SERVICES:

Oral health is an essential component of general and nutritional health. PLWH/A experience both common oral diseases and a number of painful HIV-related oral disorders, as well as complications related to HIV therapy, like Xerostomia (dry mouth). These factors often contribute to inadequate food intake resulting in poor nutrition. The efficacy of some HIV

medications is dependent upon taking them on a full stomach. PLWH/A need to initiate and maintain regular dental care. Barriers to care include provider capacity, limited funding dedicated to dental services, proximity and availability of adult and pediatric providers, unresponsiveness to requests for proposals from available dentists in certain catchment areas, inadequate physician education regarding the oral health component of treatment plans, Medicaid managed care HMOs' lack of affiliation with HIV-dedicated dental treatment programs, low Medicaid reimbursement rates for complex HIV-related dental care, inadequate adherence to recognized standards of care for oral health, and ineffective client education on maintaining good oral health through existing dental services. Such barriers are particularly pressing in southern New Jersey, such as in Atlantic, Cape May, Cumberland, and Salem Counties, where transportation services, if available, are essential to accessing dental care in Camden County.

Recommendation:

- Recognized standards of care for oral health should be promulgated by the appropriate federal authority, widely disseminated, and incorporated universally in dental and medical practices.

HOSPICE SERVICES:

Hospice services are still needed within a comprehensive package of home health care to effectively provide established core groups of terminal care services at home or in institutional settings to both adult and pediatric patients.

Recommendation:

- Planning bodies should continue to take into consideration the benefits of hospice services and actively assess the need for funding hospice care when conducting needs assessments, comprehensive planning, and priority setting activities.

HOME HEALTH CARE:

Home health services assist in preventing hospitalizations in a cost-effective manner. PLWH/A need ongoing home based and community-based care services. Skilled services include: insertion of intravenous lines, intravenous infusions, total parenteral nutrition, specialized treatments and respiratory care by nursing care specialists; physical, occupational, speech, and rehabilitation therapy; mental health and support counseling; case management; medical day care; and routine diagnostic laboratory tests. Unskilled services include durable medical equipment, nutritional supplements, and homemaker/home health aide personal care assistance. Specialized pediatric services include central line IV medications, nasogastric tubes, and oral medication.

Recommendation:

- The Title II grantee should continue to fund the standardized provision of both skilled and unskilled services under the Statewide HIV Homecare Program. Standardized features would include use of a multi-disciplinary team, inclusive of PLWH/A, family members, and caregivers of infected children, to develop a comprehensive treatment plan wherein collaboration, coordination, and review would be intrinsic at all levels of service. Standardization would also include coordination of services by case managers kept current in HIV treatment.

MENTAL HEALTH SERVICES:

PLWH/A need mental health services to improve compliance abilities and foster a greater sense of well being. The perception of HIV as a chronic illness has increased the hope of PLWH/A, but has evoked new issues, stressors, and fears, such as potential re-entry into work, long-term health/medication costs, ongoing family relationships and continued risk reduction. Mental health counseling is needed to increase an individual's coping skills around those concerns and also treat individuals with clinical depression and impaired daily functioning.

PLWH/A multiply-diagnosed with substance use and/or alcohol use, mental illness, and behavioral problems residing in specialized treatment facilities also need mental health services.

To facilitate permanency planning, PLWH/As, their affected children, and custodial caregivers need mental health services to ensure effective and supportive transitions and to equip them to manage the stress associated with the loss of a parent to HIV. Mental health support during the crucial months prior to and following the death of a PLWH/A would help in establishing stable homes for surviving children, enabling them to make successful transitions to the reconfigured family constellation.

Mental health modalities should vary, including short-term behavioral counseling, crisis intervention, individual, group, family/couples counseling, home visits and in-home treatment.

Recommendation:

- Planning bodies should continue to take into consideration the benefits of mental health treatment as a standard corollary to other medical services, and actively assess the need for continued funding when conducting needs assessments, comprehensive planning, and priority setting activities.

PHARMACEUTICAL ASSISTANCE:

The Title II AIDS Drug Distribution Program (ADDP) is the main conduit of Ryan White funds applied to pharmaceutical assistance. The ADDP provides life prolonging and life sustaining medications to low income individuals with HIV/AIDS. The program has been successful due to a generous allowable annual income for eligible applicants of no more than 500 percent of the Federal Poverty Limit (FPL). It also offers an expansive formulary of 110 medications, including drugs to treat diabetes and Hepatitis C.

ADDP has been designed for inclusiveness, and client demographics closely parallel the statewide AIDS epidemic with respect to age and gender. However, in terms of race/ethnicity, African Americans remain under-represented (51% vs. 61% statewide) and Hispanics are over-represented (23% vs. 16% statewide). The Title II Grantee, the Division of AIDS Prevention and

Control (DOAPC), believes that this disparity is a symptom of the much broader issue of the capability and desire of minority and disenfranchised populations to access and remain in care.

Recommendation:

- The Title II grantee should institute measures to rectify the comparatively low participation by African Americans in the ADDP. Standardized outreach protocols should be established to utilize face-to-face helping contacts in a number of settings to enroll African Americans in the program.

CLIENT ADVOCACY – LEGAL

PLWH/A need legal assistance for permanency planning, discrimination issues, and disputes related to housing, entitlements, and insurance/managed care issues. Increasingly, women need legal support with adoptions/foster care and domestic violence incidents. With the limited availability of affordable and safe housing, PLWH/A are also seeking assistance in accessing housing programs for the disabled and for problems related to housing discrimination and tenant/landlord disputes. Due to the dynamic environment of healthcare, managed care/insurance, and entitlements, PLWH/A may need help gaining access to quality healthcare with adequate benefit coverage. Legal advocacy is also needed to assist with entitlement appeals, eligibility issues, enrollment, quality of care, referral to specialists, and lack of confidentiality. As health outcomes improve for PLWH/A, they are returning to the workforce with a resultant potential for employment and insurance discrimination and problems arising in fulfilling welfare work requirements.

Recommendation:

- Standards of care should be developed for the provision of legal services in accordance with those established by the American Bar Association and Legal Services of New Jersey.

DIRECT EMERGENCY FINANCIAL ASSISTANCE (DEFA)

A significant number of PLWH/A are of lower socioeconomic status, and often their HIV infections exacerbate the effects of their economic status. PLWH/A, who have been self-sufficient and economically independent, can suffer serious disruptions in their economic stability due to disability from the progression of the disease. Such PLWH/A periodically are unable to financially meet their own survival needs for food, utilities, housing, and medications. DEFA continues to be needed to address such emergent shortfalls.

Recommendation:

- Planning bodies should continue to take into consideration the benefits of DEFA. Standardized protocols should be developed to build upon existing local emergency systems/resources, to ensure compliance with payment of last resort criteria, and to include measures to address self-sufficiency over the long term.

FOOD BANKS/HOME DELIVERED MEALS/NUTRITIONAL SERVICES

The need for the provision of food, meals, and nutritional supplements is consistently identified in needs assessments throughout the state. This need is primarily due to the prevalence of poverty within the PLWH/A community and resultant lack of resources to purchase the most basic of needs, food. The many barriers to the delivery of food service programs and proper nutrition for PLWH/A include lack of information about assistance programs, lack of refrigeration and cooking facilities, prohibitive qualification processes, transportation, inadequate referral assistance, personal factors, and a need for childcare while procuring services.

Recommendation:

- Planning bodies should continue to take into consideration the prioritization and design of programs for the provision of food, meals, and nutritional supplements for PLWH/A to ensure a baseline nutritional standard is attained as an underpinning to medical treatment.

EDUCATION AND TRAINING

The NJAETC, funded under Part F of the CARE Act, has made great strides in providing high quality, state of the art HIV/AIDS education and training to primary care and support service providers throughout the state. This includes facilitating the collaboration of clinical and service oriented agencies and providing hands-on experiential clinical training as well as traditional lecture based conferences and workshops.

Recommendation:

- To maintain improvements in the level of HIV proficiency and collaboration among primary care and support service providers, the NJAETC should provide continuing education and training, including programs targeted to: health care and social service providers, PLWH/A, caretakers, case managers, and clinic administrators throughout the state. Administrators and managers of provider agencies must be specifically targeted for outreach on the need to support ongoing training for staff.

HOUSING ASSISTANCE/HOUSING RELATED SERVICES

Continued shortages of affordable housing throughout the state have led to an increasing need for housing resources for PLWH/A, including emergency, transitional, and permanent supportive housing. Housing Opportunities for People with AIDS' (HOPWA) tenant based rental assistance has long waiting lists in each county in spite of complementary housing programs such as Shelter Plus and Section 8. Emergency, transitional, and permanent housing programs for both independent living and supportive housing are not sufficient to meet the requirements of PLWH/A needing housing. Barriers to accessing housing include procedural delays, such as the requirement by some programs for a mental health screening before placement, inadmissibility of active substance users, and a low level of awareness of non-Ryan White housing/shelter programs, leading to a lack of coordination with those programs.

Recommendation:

- The DOAPC, the Department of Community Affairs (DCA), and other housing-related administrators and stakeholders should collaborate to lessen affordable housing shortages

and reduce barriers to PLWH/A in accessing housing, such as procedural delays and inadequate coordination between HOPWA and non-Ryan White housing/shelter programs.

COMPLEMENTARY THERAPIES

PLWH/A have limited accessibility to competent HIV-experienced providers of such complementary therapies as chiropractic, acupuncture, and massage to assist them in pain reduction and alternative management of HIV disease manifestations. Although the NJAETC has provided information and an annual conference on this topic, increased effort is needed to improve provider understanding of the usefulness of complementary therapies in the continuum of care. Information dissemination on how to select an effective complementary therapy provider would also be beneficial. Regional differences in funding patterns for this service category by Title I EMAs results in varying and unpredictable access for PLWH/A.

Recommendation:

- The NJAETC should offer ongoing, standard training components within varied programs to improve provider understanding of the usefulness of complementary therapies in the continuum of care. The NJAETC and others should broadly disseminate to providers and PLWH/A information on how to select an effective complementary therapy provider.

HIV SPECIALTY CARE

Several articles have demonstrated that PLWH/A who receive care from providers who have experience taking care of many PLWH/A have better health outcomes. "HIV Specialist" has been variously defined. For instance, the HIV Medical Association has defined an "HIV Specialist" as a provider who delivers care to at least 20 HIV-positive patients in two years and obtains at least 15 hours of continuing professional education in HIV-specific topics annually. The NJAETC, The Academy of Medicine of New Jersey, and the DHSS remain the major sources for educating the state's clinicians about HIV on a continuous basis.

As New Jersey requires that HIV-infected Medicaid patients obtain their health care through HMOs, it is important that these PLWH/A have access to experienced "HIV Specialists," however this designation is defined in the future. Mechanisms need to be developed to enable HMOs to recognize these specially trained clinicians, including nurse practitioners and physicians' assistants, who may represent various medical specialties, as well as Infectious Diseases, Internal Medicine, Family Practice, Pediatrics, and Obstetrics/Gynecology (OB/GYN) physicians.

Recommendations:

- The NJAETC, The Academy of Medicine of New Jersey, and the DHSS, should collaboratively convene a workgroup to review the proposed definitions of "HIV Specialist" of various organizations, and to designate a specific definition as the standard one for use in providing medical services to PLWH/A in the state.

- The DHSS should assist those implementing Medicaid managed care and the contracted HMOs to recognize specially trained HIV clinicians and affiliate with them. Such "HIV Specialists" would include nurse practitioners and physicians' assistants, and may represent various medical specialties, such as Infectious Diseases, Internal Medicine, Family Practice, Pediatrics, and Obstetrics/Gynecology (OB/GYN).

- To facilitate PLWH/A receiving medical care from "HIV Specialists" such mechanisms as standing annual HMO referrals for HIV care and designation of the "HIV Specialist" as the primary care provider (to be reimbursed at the specialist's rate), should be instituted in agreements between Medicaid and contracted HMOs.

- A standard mechanism should be developed to make an "HIV Specialist" a preferred provider with expedited credentialing when established HIV-infected patients of the "HIV Specialist" must enroll in Medicaid HMOs with which the provider has no current affiliation.

DAY/RESPITE CARE

Home and community based services are needed to relieve the primary caregiver from daily responsibilities of providing care for PLWH/A, their children, partners, and/or other family members. Often, caregiver duties will prohibit caregivers from seeking and accessing medical care for themselves. Services are needed to both encourage caregivers to address their own health care needs and to provide restorative periods for the caregivers. Existing respite care programs are currently underutilized and are often criticized on service delivery methods.

Recommendation:

- Planning bodies should continue to take into consideration the prioritization and design of programs for the provision of respite care. These programs should be designed in conjunction with PLWH/A to help meet their varying needs. Respite providers and the healthcare and social services community should collaboratively establish standard protocols for engaging PLWH/A in respite.

ACCESS TO CARE

Access to care is an ongoing problem that has multiple causes and shows itself in a number of ways. Major influences on access include changes in entitlement programs, the quality and effectiveness of outreach and referral services, the availability of transportation, cultural competency and language issues, and the changing health outlook of many PLWH/A as HIV disease moves closer to becoming another manageable chronic illness. Each of these key factors is discussed below with recommendations.

BROAD GOAL FOR ACCESS TO CARE:

To increase access to care, paying particular attention to problems in the areas of outreach and referral for hard-to-reach groups, changes in entitlement programs, medical insurance, HIV as a chronic disease, transportation, cultural competency, and language capabilities.

ENTITLEMENTS, INSURANCE, AND HIV AS A CHRONIC DISEASE:

With the introduction of treatment cocktails that include protease inhibitors, the future of many PLWH/A has changed from one of continuing disability to one of increasing health and vigor, as people once thought to be on a downward spiral, face the need and desire to return to work. At the same time, eligibility requirements for Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Welfare (both General Assistance and Temporary Assistance to Needy Families (TANF)), Medicaid, and other essential entitlement programs continue to change. Multiple programs and requirements, while beneficial to many, inherently create new "cracks" for PLWH/A to fall through, and increase the need for assistance with entitlement appeals and ineligibility determination disputes.

A person on Social Security who is found to have an improvement in his/her health could be terminated from the program prematurely, even though the improvement has not yet been

established to be permanent. This type of termination may render the PLWH/A unable to obtain medications, potentially compromising improved health status. Similarly, after the five-year limit on benefits established by the Welfare Reform Bill, there are no income programs for PLWH/A who do not meet the criteria for Social Security, but are not well enough to return to work. Persons with drug convictions cannot receive welfare assistance under the Welfare Reform Act. Therefore, an unemployed PLWH/A with a drug conviction may have no legal sources of income. Persons who are undocumented and/or migratory also face similar issues.

Access to health insurance is a problem. PLWH/A ineligible for entitlements such as SSDI, SSI, Welfare, Institutional Medicaid, and FamilyCare health insurance have limited access to vital medical evaluations, primary and specialty treatments, and supportive medical programs such as day and respite care. A person denied Social Security within one calendar year is ineligible for Institutional Medicaid (insurance for nursing home placement). Similarly, a PLWH/A whose health has improved and whose new salary makes him/her ineligible for Medicaid or FamilyCare health insurance may still face an industry-imposed waiting period before employer-provided health insurance will cover the costs of protease inhibitors and combination therapy, other prescribed medications, and doctors' care.

Some employed PLWH/A' concerns about insurance portability (i.e. vis-à-vis pre-existing conditions) when changing jobs may be addressed by provisions of the 1992 Health Care Reform Act in New Jersey and the federal Health Insurance Portability and Accountability Act of 1996. For others returning to work who have not accrued sufficient continuous amounts of time under prior creditable insurance coverage (including Medicaid), pre-existing condition limits may be legally invoked by employers, making for untenable gaps in medical services and access to pharmaceuticals. Those whose COBRA premiums have been covered by the Title II Health Insurance Continuation Program may not be afforded adequate overlap to enable seamless coverage when waiting periods or management lag time prevent timely placement of returned workers onto health benefits. For returned workers with no or delayed coverage, qualifying for the AIDS Drug Distribution Program and FamilyCare health insurance may be blocked due to earnings above the respective income limits. The FamilyCare health insurance announced the closure of enrollment for adults with no minor children in the household effective September 1,

2001. The State-funded Charity Care Program for uncompensated costs, which serves only as "funder of last resort," faces tenuous funding streams under each annual legislative budget, making it a very unsecure "safety net" for uninsured PLWH/A.

In addition to these new problems with access to care, other existing problems with entitlement programs remain, such as delays in the approval process or the fact that the usual food stamp benefit does not allow for the often-costly food items that PLWH/A following health-conscious diets need in order to maintain optimal health.

Recommendations:

- PLWH/A should be allowed additional time on public assistance with input from their physicians; this would help improve compliance with their medical treatment and could save many lives.

- Social Security should not terminate persons with a clinical diagnosis of AIDS or debilitating symptomatic HIV disease simply on the bases of their responses to HAART.

- Any individual diagnosed by CDC standards as having HIV disease, who is currently on HAART therapy, should not be terminated from Social Security during the initial period of the regimen when assessment of prolonged improvement of health status and abilities of daily living is still underway.

- When PLWH/A with improved health are being re-evaluated for SSI eligibility, Medicaid should provide a transitional period of health insurance (Medicaid) until their employer-provided health insurance coverages become effective.

- Update and continue training and education for planners, providers, caregivers, and PLWH/A to deal with the issues of managing HIV as a chronic illness, including skills needed to enter (or re-enter) and succeed in the workplace.

- Mechanisms should be in place to identify problems causing delays in the approval process for benefits (SSI and SSD).

- Provide Institutional Medicaid for PLWH/A even if denied Social Security within one calendar year.

- The New Jersey Division of Family Development should establish a supplemental food stamp allowance for all eligible PLWH/A to ensure foods needed to maintain optimal health are obtainable.

- Continue public relations and outreach efforts to make families affected by HIV and providers serving them more aware of the New Jersey FamilyCare and KidCare medical insurance program to foster enrollment for those ineligible for Medicaid and without adequate medical coverage.

- Ensure adequate legal representation for PLWH/A struggling with entitlement and other issues related to living with HIV Disease.

- The State Title II grantee, under its Health Insurance Continuation Program, should continue providing health insurance premium payments while PLWH/A are unemployed or on disability, and should conduct a statewide informational campaign to educate people about the Health Insurance Continuation Program.

- Identify and facilitate access to innovative methods of extending health insurance benefits to survivors of PLWH/A.

OUTREACH, REFERRAL, COUNSELING AND TESTING

Improved outreach and referral services are needed to ensure optimum usage of established networks of HIV care throughout the state. Currently, evidence shows that a notable number of PLWH/A are not connected to any HIV-related service. Many individuals seek their first form

of primary care through the emergency room, presenting with advanced, rapid disease progression. Often individuals deal with a positive diagnosis as well as the ramifications in the STD clinic or HIV counseling/testing site without the further intervention of HIV-dedicated helping professionals. Even though effective outreach and referrals are key to effective access to care, outreach workers are generally not included as integral members of a team. Additionally, outreach workers do not necessarily receive critical training in linking consumers to services. Referral methods are not centralized. This negatively impacts such important resources as legal advocacy, which is often needed to open the door to a broader array of services.

Recommendations:

- Hire PLWH/A as outreach workers and involve them in the design of outreach and referral training.

- Augment case management models to include a team approach utilizing a supervisor, case manager and outreach worker.

- Identify outreach and referral "best practices" and provide outreach workers with uniform training in outreach and referral strategies and techniques for involving PLWH/A from hard-to-reach groups, such as substance users and others. Train outreach workers in note taking, documentation, communication skills, cultural sensitivity, harm reduction, resource identification, and follow-up of care plans.

- Have planning bodies consider establishing centralized referral efforts which include core resources, such as legal advocacy.

- Continue to provide outreach to HIV infected pregnant women to help ensure that their care will be sustained, thus protecting both mother and infant.

TRANSPORTATION

Providing transportation on routine, as-needed and emergency bases is key to enabling many PLWH/A, particularly those from low-income and hard-to-reach groups, to gain regular, ongoing access to needed health care, nutrition, and support services. This includes regularly scheduled transportation for accessing out-of-county medical services. Not enough transportation is available beyond the standard hours of 9-to-5 for PLWH/A to access support groups, drug and alcohol group meetings, food banks, congregate meal programs, and evening medical appointments.

Recommendations:

- Make transportation services available through voucher and/or fare reimbursement programs, as no single program can address everyone's needs for transportation.

- Provide transportation beyond the standard hours of 9-to-5.

- Title I EMAs and Title II Consortia should re-evaluate the current delivery system to determine its effectiveness and impact on the HIV/AIDS community, and scattered transportation sites should be considered, with each provider required to include at least one out-of-county destination in its proposal.

- Have care providers access their clients via mobile vans at welfare hotels, substance use treatment centers, homeless centers, and other areas. Ideally, such mobile vans should provide a wide range of services through collaboration with other agencies and programs, and not have lettering that includes the words "HIV" or "AIDS" so that they avoid discouraging or stigmatizing use of their services.

- Develop a unified protocol, as a standard condition in every Transportation RFP, for eligibility for transportation services where clients first access non-Ryan White-funded transportation services for which they qualify before being permitted to use Ryan White-funded services.

- Provide transportation services based on eligibility and need, not simply the "choice of the consumer."

CULTURAL COMPETENCY AND LANGUAGE

Cultural competency includes sensitivity to and adequate representation of targeted racial/ethnic/gendered populations and other relevant sub-groups in planning bodies, staff, and boards of directors of provider organizations, as well as being able to draw on staff and other resource-people fluent in languages other than English pertinent to the targeted populations. It also includes understanding the norms and styles of various hard-to-reach groups, such as IDU and others. Lack of cultural competency and multilingual providers poses significant problems, particularly for hard-to-reach groups, a large segment of PLWH/A migrant workers in the southernmost counties, and other immigrants throughout the state.

Recommendations:

- Provide for cultural competency and cultural sensitivity in the hiring and appointing of people to carry out planning and service delivery.

- Provide training and education:
    a. That involve members of relevant cultural or sub-groups in designing, presenting and evaluating training and education;

    b. That increase cultural competence and sensitivity of all planners and service providers (Ryan White-funded and non-Ryan White-funded), since no one is likely to be competent in dealing with all cultures and sub-groups;

    c. That increase the ability of outreach workers, case managers, peer and health educators, and service providers to communicate and provide needed information in a culturally and linguistically sensitive manner;

d. To PLWH/A, which take into account culture, language, and appropriate literacy and illiteracy.

e. To administrators of organizations in methodologies to improve diversity of boards of directors so that they will reflect the populations they serve.

- Prepare written materials in appropriate literacy levels and have translations into various languages, reviewed, and edited by individuals of the native language.

MARGINALIZED GROUPS WITH SPECIAL NEEDS

Six (6) socially marginalized groups with special needs make up the majority of PLWH/A in New Jersey:

1. Injecting drug users (IDUs)
2. Low-income black and Hispanic women (and their infants and children),
3. Incarcerated people, including recently released and/or on parole
4. Seniors
5. Undocumented/Immigrants
6. Youth/Orphans to AIDS (and their kin)

These PLWH/A, who may belong to two or more of the listed groups, can be some of the most challenging people to work with effectively. Discussion by category of their needs, barriers to care, and engaging them in prevention and treatment follows. Suggested recommendations pertinent to all groups appear immediately below while recommendations specific to each category are made within those categories.

BROAD GOAL REGARDING GROUPS WITH SPECIAL NEEDS:

To increase the effectiveness of planning, involvement, and treatment for IDUs, low-income Black and Hispanic women, their infants and children, incarcerated people, seniors, undocumented/immigrants, orphans to AIDS and their kin, youth, and other groups of PLWH/A with special needs, including links to HIV prevention services for marginalized groups with special needs.

Recommendations (all groups):

- Have planners and providers assess the levels of need and barriers to care of these and other groups within the relevant catchment area and ensure that the groups with special needs are taken into account, planned for, involved, and served effectively.

- Provide Ryan White and non-Ryan White planners, administrators, service delivery staff, health care providers, corrections employees, senior and youth workers, immigration advocates, and substance use treatment staff with on- and off-site training and education. The training should be designed to increase HIV/AIDS planners' and providers' understanding of the specific needs and barriers to care of groups with special needs as well as their ability to work, communicate with, reduce barriers to care and serve these groups. This would include cultural and linguistic sensitivity and competence, and ways to build trust and understanding when developing relationships with members of the target groups.

- Involve representatives of IDU, low-income Black and Hispanic women, incarcerated people, seniors, immigration advocates, youth, orphans and their kin, and other groups with special needs in planning, implementing, and evaluating training and service delivery targeted to these groups.

PROBLEMS AND BARRIERS FOR INJECTING DRUG USERS:

Injecting drug use remains the leading cause of HIV infection in New Jersey. Use of street drugs can seriously affect a PLWH/A's response to medical care, since following a complex medical regimen or keeping appointments is not a priority when the PHLW/A is under the influence. Many IDUs and substance-using PLWH/A are labeled as "difficult" simply due to their previous histories and/or current addiction/use. This affects, among other things, their abilities to obtain and keep housing. Health care providers often do not understand addiction, and respond inappropriately and communicate ineffectively with patients who are substance dependent. Conversely, substance users often have a high level of mistrust of people outside of their world. It is difficult to involve IDUs, even recovering IDUs or those working in substance use programs, in HIV-related planning and service delivery because of the above-mentioned mutual mistrust, as well as the nature of the addiction process. More treatment facilities and outpatient programs for substance users are needed, as are more support groups that address the PLWH/A's areas of concern, including programs designed for youth and young adults.

Recommendations:

- Expand the availability of substance use treatment facilities and outpatient programs so that sufficient treatment slots, support groups, and interventions designed for youth and young adults may be targeted to IDUs with HIV/AIDS.

- Provide Ryan White and non-Ryan White planners, administrators, service delivery staff, health care providers, corrections employees, immigration advocates, senior and youth workers, and substance use treatment staff with on- and off-site training and education designed to:

    - Increase substance use treatment program staff's understanding of and ability to assess the needs of, serve, and make appropriate referrals for substance users with HIV/AIDS;

    - Increase HIV/AIDS providers' understanding of addiction, IDUs, substance use and substance use treatment resources and issues, including how they can affect serving PLWH/A;

    - Increase PLWH/A' ability to participate in their own care and treatment by improving their awareness and understanding of harm reduction techniques, available treatments, potential side effects, drug interactions, and the need for follow-up;

    - Increase medical providers' awareness of the types of drugs, both prescription and non-prescription, that PLWH/A may be using and the need for more intensive pain management for substance users;

    - Increase the understanding of substance users and how to work effectively with substance using PLWH/A among staff members of agencies and programs primarily concerned with homelessness, e.g. shelters, etc.

PROBLEMS AND BARRIERS FOR LOW-INCOME BLACK & HISPANIC WOMEN:

Twenty-seven percent[viii] of known cases of HIV infection in New Jersey occur among women who are predominately Black or Hispanic, and largely low-income IDUs or sex partners of IDUs. Cultural gaps between providers and this group make recruiting and involving them in planning, prenatal care, and medical treatment challenging. Similar problems arise in attempting to treat their infected infants, children, and youth. In addition, many of these women are mothers whose priority is caring for their children, and/or providing care for an infected or ill male partner, often to the exclusion of their own medical needs. The high proportion of cases among this at-risk population, most of whom are of child-bearing age, makes the need to reduce perinatal transmission of HIV, by implementing the most recent treatment protocols and behaviorally-based adherence techniques, a major priority.

Recommendations:

- Provide Ryan White and non-Ryan White planners, administrators, service-delivery staff, health care providers with on- and off-site training designed to increase their understanding of the specific needs and barriers to care of low income Black and Hispanic women, including cultural and linguistic sensitivity and competence.

- Enhance care and treatment service delivery in such ways as co-location of adult and pediatric medical services, flexible program hours, i.e. evenings, weekends, and concrete services such as transportation and childcare.

- Continue intensive efforts to engage pregnant women in prenatal care via such interventions as van outreach in targeted cities, and refinement of protocols for HIV testing and provision of HAART therapy prenatally and during labor/delivery for the further reduction of perinatal HIV transmission.

PROBLEMS AND BARRIERS FOR INCARCERATED PEOPLE:

In part because of the obvious correlation between HIV, drug use, and criminal conviction, many PLWH/A in New Jersey are incarcerated in county, state, and federal institutions within the state[ix]. The quality and frequency of HIV-related services available within institutions vary considerably, depending on the system (i.e., state vs. county) and facility. The same is true of release planning and post-release follow-through to ensure continuity of services. Particular issues of concern include: early identification of HIV infection, especially among incarcerated youth; availability of broad prevention activities and substance use treatment; relaxation of condom distribution prohibitions; appropriate access to prenatal and perinatal care for HIV infected women who are incarcerated; appropriate access to HAART at all levels of incarceration to ensure compliance with the uniform standard of care for all PLWH/A. Other concerns include appropriate access to pain management, palliative, terminal or hospice care programs; coordinated release planning and post-release follow-through; and continuing education to increase the skills and knowledge of correctional institutional staff regarding HIV prevention, care and treatment.

Recently awareness has increased regarding the fact that the concentration of PLWH/A in correctional facilities presents a "public health opportunity." While this is true, correctional facilities are not structured, designed, or dedicated to be public health agencies. They do not have the mission, assets, or technical knowledge to take full advantage of this public health opportunity. Therefore, it is critical that state and local public health agencies and appropriate community based organizations take affirmative action to build relationships and collaborate with local, county, state, and federal correctional facilities in this regard, in order to allow their unique assets to reach the community members who are temporarily incarcerated. Some recent progress has been made in this regard with demonstration projects focused on education, prevention, early detection, release planning, and continuity of care. Such programs should be expanded.

Recommendations:

- Encourage and promote "Inreach" efforts by public health agencies and community based organizations whereby their services are extended into correctional facilities at all levels.

- Establish programs of release planning for incarcerated PLWH/A in order to promote a better "bridge" to community based care services and to facilitate continuity of care.

- Encourage and promote ongoing training on HIV topics to institutional staff (administrative, custodial, and professional health care personnel) of correctional facilities. Training should increase internal caregivers' and providers' understanding of and ability to do release planning and provide treatment to incarcerated PLWH/A.

PROBLEMS AND BARRIERS FOR SENIORS:

Over 10% of Americans who test positive for the virus are over 50 years of age. This is a largely overlooked at-risk population. Education for seniors reaches very few of them for many reasons. These include general avoidance of the fact that older adults are sexually active, lack of initiative on the part of HIV professionals, lack of interest on the part of senior organizations, as well as the failure of seniors to realize their personal risk for infection during sex. Substance/alcohol use further complicates matters, as does homelessness and generation-to-generation problems. Few doctors are expert in both HIV/AIDS and gerontology.

HIV testing is another area that needs immediate attention, as does the need to certify seniors as educational presenters and peer counselors. The input of seniors should be sought during HIV/AIDS education, counseling and testing situations. Older adults have particular needs and fears specific to their population. The issues of seniors already infected with HIV, even into the final stages of AIDS, should be addressed. Substance and alcohol use in seniors as it relates to HIV/AIDS require appropriate interventions.

Recommendations:

- Planning bodies should include in their needs assessment and priority setting activities methodologies to glean and utilize for priority rankings information about seniors' potential needs for HIV services in their catchment areas.

- Planning bodies should include in their membership representation from the senior community and/or senior services' providers.

- Clinicians treating seniors should take sexual and drug use histories and include HIV prevention messages and other appropriate interventions in their care plans for senior patients.

- Outreach campaigns to increase HIV testing should include seniors as a targeted population.

- Programs using peer outreach methodologies should recruit and utilize senior peers for targeted outreach to this population.

PROBLEMS AND BARRIERS FOR THE UNDOCUMENTED PERSON:

Existing literature demonstrates that the undocumented population disproportionately lacks health coverage and receives fewer health services than native-born citizens of the United States[xi]. Though reliable numbers are unavailable, the impact of HIV/AIDS is assumed disproportionately higher among this population that possesses few available options for care. The widely used term "immigrant" includes undocumented persons and non-immigrants such as students, visitors, as well as persons awaiting status adjustment or deportation. Immigrants face access and coverage disparities largely because of policy changes including the law that changed the United States welfare system and the Personal Responsibility and Work Opportunities Reconciliation Act of 1996 (PRWORA).

Under the Act, undocumented persons are only eligible for emergency Medicaid coverage. An emergency is defined as:

> "A medical condition (including labor and delivery) manifesting itself by acute symptoms of sufficient severity (including severe pain) such that the absence of immediate medical attention could reasonably be expected to result in (a) placing the patient's health in serious jeopardy, (b) serious impairment of bodily functions, or

(c) serious dysfunction of any bodily organ or part."

In addition to Ryan White-funded health and support services, the immigrant population is also eligible for public health services funded through sources other than Medicaid, usually provided by county health clinics and Federally Qualified Health Centers (FQHCs). The county and FQHCs' services include primary care, TB and STD screening, diagnosis and treatment, as well as HIV and AIDS services. Despite eligibility for emergency Medicaid, Ryan White-funded care, and other services, members of the immigrant population face perceived and real obstacles to their accessing care for HIV/AIDS clinical services.

Recommendations:

- Provide education to planners, administrators, providers, and the immigrant population to eliminate confusion over immigrants' eligibility for programs and those services available to them. Include in such educational programs instructional units on cultural and linguistic sensitivity and competence.

- Planning bodies should assess the need for intervention services to immigrants to assist them in reducing the fear of being reported to the INS, among other barriers, and such services should be prioritized for funding in accordance with the catchment area's need.

- Design a strategy to address the perceived and real costs charged for health care, that now preclude persons from accessing care, which would maximize utilization by immigrants and the undocumented of existing programs for which they are financially eligible.

- Include immigrants and representatives of undocumented populations and/or their advocates in HIV/AIDS planning, prevention and service program design, delivery, and evaluation.

YOUTH/ORPHANS TO AIDS AND THEIR KIN

New Jersey ranks third in the nation for pediatric HIV cases; this includes vertical (perinatal) infection as well as acquired infection. With HIV now a chronic illness, the survival of HIV-infected infants through childhood and even adolescence has increased, making data on teens' behavior highly relevant. One in four sexually active teens gets a sexually transmitted disease (STD) every year. Yet, 68% of sexually active 15-17 year olds do not consider themselves to be at much risk. Most (57%) have never discussed STDs with a health care provider, and 70% have never been tested. One in four (25%) of sexually experienced 15-17 years olds, reports having ever been tested for HIV; 29% for other STDs. The median age at first intercourse is 16.5 years. Teens from poor families are more likely, compared to teens from more affluent homes, to initiate sexual intercourse and are less likely to use contraception. By the age of 24, at least one in three sexually active people is estimated to have contracted a STD.

In addition, proponents of abstinence-only education argue against any discussion or education about alternative lifestyles, contraception, and safer sex, asserting that these send young people mixed messages that contradict the absolute prescription of abstinence and encourage sexual activity.

As for the HIV-infected youth, the entitlements conferred during childhood last into their "adulthood" at eighteen years of age. This necessitates consideration of adult means of ensuring financial support and health care services for this population. Also, these youth are at risk for becoming pregnant, turning to drugs, ending up in the criminal justice system, and either transmitting or being re/infected with HIV and/or STDs.

In New Jersey, an estimated 12,000 children have lost their parent(s) to AIDS, and another 18,000 are estimated to be currently living with parents or heads of households who have AIDS. Regarding the children orphaned to AIDS, many have been placed in kinship care. The American Bar Association uses an expanded definition of "kin" as any relative by blood or marriage, or any person with close personal, emotional, or familial ties to another. Often the kin is the grandmother or older sibling.

The kin may be the primary care giver of the infected parent before his or her passing, and they often live in subsidized or substandard housing. After the death of the parent, the children sometimes move in with such kin. In another scenario, following the death of a family member with AIDS, survivors, including kin caregivers, are usually required to vacate the AIDS-dedicated housing unit within 12 months. The cut off of AIDS-related housing assistance and the lack of adequate housing have been major obstacles.

In addition, the kin/caregiver usually receives no support other than $162.00 a month in financial assistance. However, orphaned children in foster care with a non-relative have a fuller financial subsidy allowed by the Division of Youth and Family Services, including Medicaid insurance and transportation, eligibility for daycare, clothing allowances, and other state supported services.

Twenty years into the epidemic, no federal initiatives have addressed the needs of children affected by HIV/AIDS. These children need a network of support and services that gives them a chance of succeeding despite their being from minority groups, poor, and/or parentless.

Recommendations:

- State, local and private agencies should insure that funding and public/private partnerships are made available for youth and family support services including after school programs, mental health counseling, health services, and legal assistance for youth and families with HIV/AIDS and to the children who have lost their parents to AIDS.

- Provide outreach to HIV infected and at risk youth (including juvenile justice and adult correctional facilities) to help ensure that their care will be sustained.

- Link youth at risk and/or infected with HIV/STDs to appropriate access to HIV/ STDs care, including medical, case management and entitlement specialists.

- Inform policymakers that youth are making “adult” decisions before reaching their majority, and they should be afforded information regarding their health, benefits, and

support services, and permitted to make decisions without the signed waivers, consents, and/or the presence of guardians, if necessary. This should include access to HIV counseling and testing without parental/guardian consent for those under the age of 18.

- As youth with HIV turn 18, Social Security evaluations of their eligibility for SSI, sometimes in the context of lost Social Security survivors' benefits, should be flexible in providing for a transitional period of health insurance (Medicaid) and financial benefits to assist youth with the adjustment to adulthood.

- Children orphaned to AIDS and placed with kin should be afforded the same stipends and services given to children placed in foster care.

- Insurance programs should revise their limitations on the type and amount of mental health services for children affected by HIV/AIDS so that services reflect patient needs and not arbitrary limits.

- Children of undocumented PLWH/A should receive full access to health care, mental health, and social services without being penalized, including being reported to the INS.

- Public social service agencies and housing authorities should develop an extended range of housing services that support and subsidize low-income individuals and families affected by HIV who choose to care for orphaned youngsters.

- Policymakers should recognize and change the definition of "family" to "kin," which includes all combinations of family (individually defined) without exclusions, more specifically any non-traditional family arrangement.

HIV PREVENTION AND SPECIAL NEEDS GROUPS:

For all PLWH/A groups, including those who are socially marginalized with special needs, it is essential to provide prevention interventions within the scope of care and treatment programs

PLWH/A must become involved in HIV prevention programs. In the past, few prevention programs have been directed towards HIV positive persons. Slowly, HIV prevention programs are realizing the importance of taking their prevention message to marginalized individuals who are HIV infected. Primary prevention means not only preventing a high-risk individual from acquiring HIV but preventing an HIV infected person from transmitting the virus. Although primary prevention is essentially targeted at HIV negative people and intends to keep them negative, information needs to be given to individuals who are receiving HIV care and treatment services that will prevent the transmission of HIV from the infected person to the uninfected. Providers should continue secondary HIV prevention, which is intended to delay the onset of HIV related illnesses by getting PLWH/A to change their behavior so as not to re-infect themselves with additional strains of HIV, or acquire other infections (STDs or Hepatitis).

Recommendations:

- Co-locate prevention programs and Ryan White care and treatment programs to ensure the involvement of HIV prevention case managers and health educators in treatment planning for marginalized PLWH/A with special needs.

- Train health care providers to reinforce prevention messages or to deliver the prevention message if PLWH/A are not able to receive services of prevention programs. Prevention messages should address issues of re-infection and prevention of STDs and other infectious diseases.

MANAGED CARE

In 1996, Medicaid Managed Care (MMC) became a reality in New Jersey with mandatory enrollment of recipients of Temporary Assistance for Needy Families (TANF) into Medicaid-approved HMOs. In year 2000, MMC was instituted among disabled, blind, and aged populations receiving Supplemental Security Income. It began in the three Counties of Hudson, Camden, and Mercer, and the rollout schedule has continued in 2001 to bring on board the other 18 counties.

PROBLEMS AND BARRIERS

Some PLWH/A enrolled in MMC have been severed from long-standing relationships with their HIV specialists and have reported concerns that HMO primary care providers (PCPs) do not have the experience and are not knowledgeable about the rapidly evolving U.S. Department of Health and Human Services clinical guidelines for treatment of HIV disease.

The Office of Managed Health Care at Medicaid reports that its review of clinicians available through the contracted HMOs for specialty needs in treating the various acute and chronic illnesses, showed that seventy percent of the specialists had affiliations with the contractors. The Office had delayed contracting with the approved HMOs for three months because the proportion of specialists had not reached this minimal proportion. Thirty percent non-participation by specialists in Medicaid-contracted HMOs is too large a deficit when considering the many specialists brought to bear in treating PLWH/A.

BROAD GOAL REGARDING MANAGED CARE:

To complement and help enhance Medicaid Managed Care (MMC) and other managed care providers' effectiveness in treating HIV/AIDS and serving PLWH/A.

Recommendations:

- The DHSS will continue to work closely with the Department of Human Services Medicaid Office of Managed Health Care to:

    - Ensure that the federal standards of care for PLWH/A (both adult, women, and pediatric) are adhered to through established agreements with MMC companies to utilize existing centers of treatment excellence, including following all HIV-exposed infants and HIV infected children and youth at a pediatric HIV network site;

    - Ensure that HIV infected pregnant women are informed before delivery of HIV options for themselves and for their child, including adherence to state laws regarding HIV counseling for all pregnant women;

    - Create "special needs" provisions regarding access and treatment of HIV/AIDS and PLWH/A that managed cared organizations must meet to qualify for and remain involved in MMC (including use of decision-makers who are experienced and clinically competent in dealing with HIV/AIDS, coverage for day and respite care services, etc.);

    - Address the issues and barriers resulting from "auto-assignment", including the identification of the process (including responsible individuals at each level) to quickly resolve grievances and complaints from PLWH/A s, so that access to appropriate care is not interrupted or stopped;

    - Increase capitation payments for delivering care to patients in various disease stages according to viral load, CD4 count, and other co-morbidity conditions (e.g., Hepatitis, TB, substance use, homelessness, etc.), as well as allow specialists to act as PCPs and receive the specialist's reimbursement rate;

- Ensure that experienced members of the HIV/AIDS community, including both providers and PLWH/As, are involved in the ongoing planning and refinement of MMC at the state level;

  - Compile and make available to MMC companies and PLWH/A up-to-date lists of all HIV-experienced primary care providers (not just infectious disease specialists) in each catchment area, including those experienced in treating women and children, qualified dental health providers, as well as appropriate advocacy/grievance procedures and resources;

- Incorporate appropriate MMC and other managed care representation on local planning and coordination bodies in order to identify PLWH/A needs vis-à-vis MMC and other managed care providers, services and systems, communicating them to MMC and other managed care companies, and working cooperatively to meet them;

- Require as part of their contract(s) that MMC and other managed care administrators and providers participate in relevant training, education and updates regarding medical management of HIV, treatment regimens, primary and secondary prophylaxis, psychosocial issues, cultural diversity and sensitivity, and outreach strategies to IDU, as well as ensuring exposure to and developing linkages with, providers experienced in treating HIV/AIDS;

- Develop cooperative and complementary efforts with MMC and other managed care systems and providers to meet the needs of PLWH/A, including outreach, referral, transportation, follow-up and other supportive services;

- Planning councils and planning bodies, including consumer groups and consortia, should work to establish local and regional liaisons and working relationships with MMC and other managed care systems and providers.

- All bodies (including planning councils and consortia, service providers, case managers, ASOs, etc.) should continue to work with PLWH/A to help them understand available services and communicate and work effectively with MMC and other managed care systems and providers.

CONCLUSION

While much progress has been made since the 1998 SCSN in working toward achievement of the four broad goals identified for New Jersey, research to modify the document confirmed the still current validity of those goals. Ryan White planners, administrators, service providers, and consumers still need to be engaged in ongoing work within the goal areas of Standards and Quality of Care, Access to Care, Marginalized Groups with Special Needs, and Managed Care.

The thriving networks of care developed as a result of the Ryan White CARE Act, while comprehensive in scope, have not eliminated all barriers and gaps within the service delivery systems. It is the intent of this document that barriers and gaps identified through the comprehensive efforts of SCSN Task Force members and discussed herein may be lessened in number and narrowed in scope by an honest review and sincere application on the part of HIV community stakeholders of the recommendations of this document. These have been kept broad in scope in compliance with the guidance from HRSA and in deference to the local planning mandates intrinsic to the Ryan White CARE Act tenets.

This SCSN is therefore recommended for best use in the local planning processes as a documentation of the broad array of problem areas still confronting PLWH/A in the state and the generalized measures to be undertaken in tackling those problems. HIV community stakeholders are challenged with drawing from the generality found here while filling in the specifics particular to their catchment areas' needs. SCSN recommendations form the ideal around which local concrete interventions in the form of programs and services need to be devised. In that spirit of proactively moving from the conceptual to the real, HIV stakeholders throughout the state may be ensured of steady improvement in the continuum of HIV care for their communities.

Appendix A: SCSN Task Force Members - Document Preparation

Title I

Vernon R. Burkhart
Hudson County EMA

Hope E. Heldreth
Cumberland County EMA

Marvin Krieger
Hudson County EMA

Bruce McElrath
Philadelphia EMA

Elena Perez
Newark EMA

Akin Sogo
Philadelphia EMA

Wanda M. Tugman
Paterson-Bergen-Passaic EMA

Karen J. Walker
Paterson-Bergen-Passaic EMA

Title II

Patricia Buckley
Monmouth-Ocean Consortium

Wayne A. Brown
Mercer Consortium

Bryan C. Cole Smith, M.Ed.
Burlington-Camden-Gloucester-
Salem Consortium

Donald A. Griesmann
Atlantic-Cape May Consortium

Chas White
Mercer Consortium

Title III

Anita Vaughn, M.D
Newark Community Health Centers

Title IV

Jane Caruso
NJ Department of Health & Senior Services
Division of Family Health Services

Kimberly Connolly
Jersey Shore Medical Center
NJ Family Centered HIV Care Network

Amanda Rubio
UMDNJ/Robert Wood Johnson
Medical School
NJ Family Centered HIV Care Network

Appendix A: SCSN Task Force Members - Document Preparation (Continued)

Part F

Evelyn Granger
Special Project of National Significance
UMDNJ Adolescent and
Young Adult Medicine

Dion Richetti
NJ AIDS Education
and Training Center

Additional Expertise

Patricia A. Carey
NJ Department of Health & Senior Services
Housing Opportunities for People with AIDS

Stewart D. Grossman
HIV Prevention Community
Planning Group

Thomas D. Farrell
NJ Department of Corrections

Patricia A. Nisler
NJ Department of Health &
Senior Services
Staff to SCSN Task Force

Keith Fullmer
Criminal Justice, Substance Use

Phoenix Smith
NJ Department of Health &
Senior Services
Title II Liaison to Title I EMAs

Craig Beneke
Title III, Pennsylvania

ACKNOWLEDGEMENTS

The Statewide Coordinated Statement of Need Task Force wishes to express its appreciation to Linda S. Podhurst, PhD, of the University of Medicine and Dentistry of New Jersey, Francois Xavier Bagnoud Center, Newark, for her contribution of survey results on the utility of the 1998 SCSN.

The Task Force also wishes to acknowledge the important contribution of Lawrence R. Kane of the New Jersey Department of Health and Senior Services, Division of AIDS Prevention and Control, for his compilation of HIV surveillance data for this document's Epidemiological Profile.

Appendix B: Additional SCSN Task Force Members

Title I

David Ajuluchukwu
Newark EMA

Maria D. Irizarry
Newark EMA

Tom Jones
Middlesex-Somerset-Hunterdon EMA

Title II

Shannon Hastings
Monmouth-Ocean Consortium

Title III

Brian McGovern
UMDNJ University Hospital

Part F

John Jandinski, D.M.D.
UMDNJ NJ Dental School

[i] "NJ HIV/AIDS Cases Reported as of March 31, 2001," NJ Department of Health and Senior Services - HIV/AIDS Surveillance Program.

[ii] "NJ HIV/AIDS Cases Reported as of March 31, 2001," NJ Department of Health and Senior Services - HIV/AIDS Surveillance Program.

[iii] "Success in Implementing Public Health Guidelines to Reduce Perinatal Transmission of HIV: Louisiana, Michigan, New Jersey, and South Carolina, 1993, 1995, and 1996," MMWR, Centers for Disease Control and Prevention, 1998.

[iv] "NJ HIV/AIDS Cases Reported as of March 31, 2001," NJ Department of Health and Senior Services - HIV/AIDS Surveillance Program

.

[v] "NJ HIV/AIDS Cases Reported as of March 31, 2001," NJ Department of Health and Senior Services - HIV/AIDS Surveillance Program.

[vi] "Success in Implementing Public Health Guidelines to Reduce Perinatal Transmission of HIV: Louisiana, Michigan, New Jersey, and South Carolina, 1993, 1995, and 1996," MMWR, Centers for Disease Control and Prevention, 1998.

[vii] "NJ HIV/AIDS Cases Reported as of March 31, 2001," NJ Department of Health and Senior Services - HIV/AIDS Surveillance Program

.

[viii] "NJ HIV/AIDS Cases Reported as of March 31, 2001," NJ Department of Health and Senior Services - HIV/AIDS Surveillance Program.

[ix] "NJ HIV/AIDS Cases Reported as of March 31, 2001," NJ Department of Health and Senior Services - HIV/AIDS Surveillance Program.

[xi] "Immigrants' Health Care: coverage and Access," The Kaiser Commission on Medicaid and the Uninsured, August,